

Los Angeles County Commission on HIV



Community Listening Sessions Report Part 1: Undocumented Individuals, Women of Color, Aging/Older Adults, and Service Planning Area 1 (Lancaster/Antelope Valley)

This report is a collaborative effort of the:
Los Angeles County Commission on HIV
Division of HIV and STD Programs, Department of Public Health
NCLR/ California State University Long Beach (CSULB) Center for Latino Community
Health, Evaluation, and Leadership Training

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Overview

The NCLR/CSULB Center for Latino Community Health, Evaluation and Leadership Training staff conducted four focus groups with various target audiences (undocumented, women of color, aging/older adults, and service planning area 1) to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Methodology

Recruitment

All focus group target recruitment was coordinated by the Los Angeles County Commission on HIV. All groups were scheduled and implemented within a one-month period in Spring 2016 in different locations in Los Angeles County.

Instruments

Consent forms and demographic surveys were developed by the Los Angeles County Commission on HIV and provided to the NCLR/CSULB Center Evaluation Team to administer prior to the focus group (Appendix A). The Los Angeles County Commission on HIV Team developed the focus group guide, and survey questions. The NCLR/CSULB Center Evaluation Team provided translation of the survey into Spanish. Focus group questions were designed in order to understand HIV care and prevention service gaps and opportunities in Los Angeles County.

Focus Group Facilitation

Each focus group was moderated by experienced and trained bilingual NCLR/CSULB Center evaluation staff who are certified in the protection of research subjects' rights. Focus group participants were greeted, thanked for their participation, engaged in informed consent procedures by the moderator and note taker(s), and all provided written and verbal agreement to participate in the focus group discussions. Each focus group was digitally recorded and each session lasted approximately 90 minutes. The digital recording was sent to a transcription service, which typed up and translated the discussion when needed. The English transcriptions were provided to the NCLR/CSULB Center staff for analysis.

Analysis

The survey data was entered, cleaned and analyzed by NCLR/CSULB Center staff using Statistical Program for the Social Sciences (SPSS) (IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.) for descriptive statistics.

The transcripts were coded in Dedoose (Version 7.0.23, web application for managing, analyzing, and presenting qualitative and mixed method research data (2016). Los Angeles, CA: SocioCultural Research Consultants, LLC, www.dedoose.com) by three independent coders. Using the questionnaire guide and the debriefing notes as base documents, the moderators and note-takers met

as a team to discuss potential codes and to create a preliminary codebook. New codes were added after periodic team meetings and transcripts subsequently re-reviewed for additional categories. The survey results are presented first, followed by the discussion findings.

Results

Demographic Characteristics

The CSULB Center facilitated four focus groups as part of the evaluation process for the Los Angeles County Commission on HIV. Table 1 displays the logistics of the focus group facilitation.

Table 1. Focus Group Description

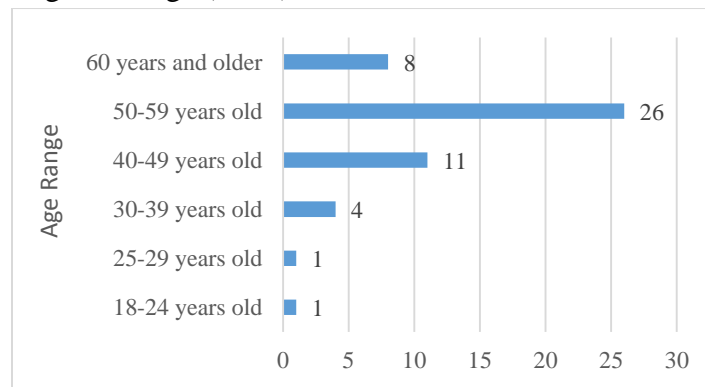
Focus Group No.	Target audience & Language of Focus Group	Date & Time of day	Location	No. of people	Moderator	Note Taker
1	Undocumented Spanish	4-Apr-16 6:00-7:30pm	Plaza de La Raza, 3540 N. Mission Rd, Los Angeles, CA 90031	14	Mara Bird, PhD	Erika Gonzalez, MA
2	Women of Color English	6-Apr-16 6:00-7:30pm	COH office, 3530 Wilshire Blvd, Suite 1140, Los Angeles, CA 90010	13	Mayra Rascon, MPH, MS	Erika Gonzalez, MA
3	Aging/Older Adults English	13-Apr-16 6:00-7:30pm	COH office, 3530 Wilshire Blvd, Suite 1140, Los Angeles, CA 90010	11	Mayra Rascon, MPH, MS	Erika Gonzalez, MA
4	Service Planning Area 1 English	2-May-16 12:30-2pm	907 West Lancaster Boulevard, Lancaster, CA 93534	17	Mara Bird, PhD	Erika Gonzalez, MA

Focus Group Demographic Results

The focus groups consisted of a total of 55 participants from Los Angeles County. Three respondents indicated that they were HIV negative and these surveys were excluded in the analysis due to the small number. However, it should be noted that a better and targeted recruitment of high-risk negatives should be considered for future projects. One person declined to answer the survey entirely; that survey was also excluded from the analysis. The results presented below therefore reflect information from 51 participants.

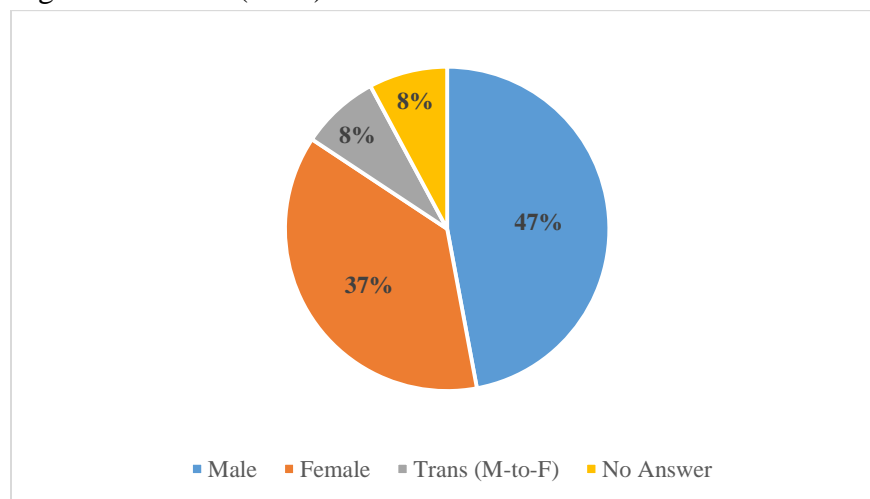
Focus group participants were primarily 50+ years old (n=34). Figure 1 displays the age range of all participants.

Figure 1: Age (n=51)



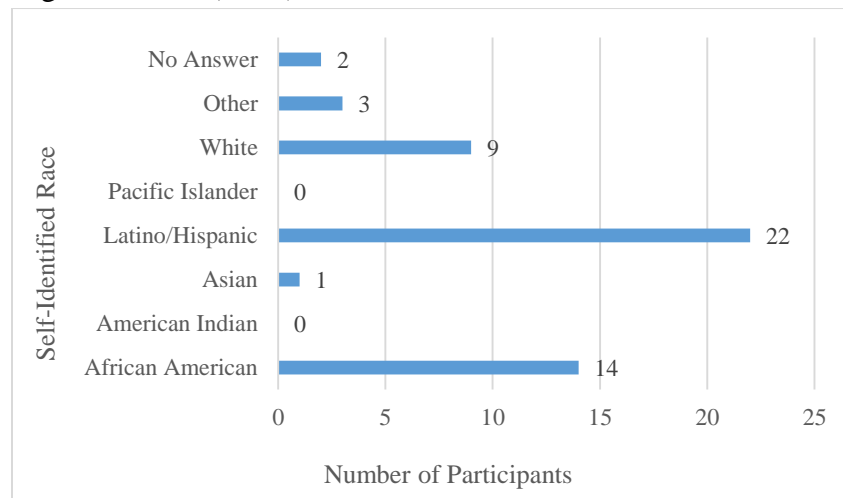
More males (47%) than females (37%) participated in the focus group. Figure 2 presents the gender of the participants.

Figure 2. Gender (n=51)



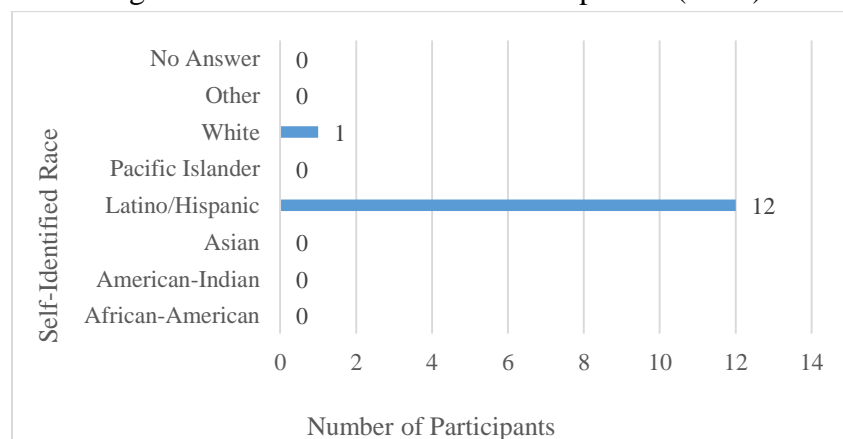
A majority of participants were Latino (n=22), followed by African-American/Black (n=14), and White (n=9). Figure 3 displays the race and/or ethnicity of all participants.

Figure 3. Race (n=51)



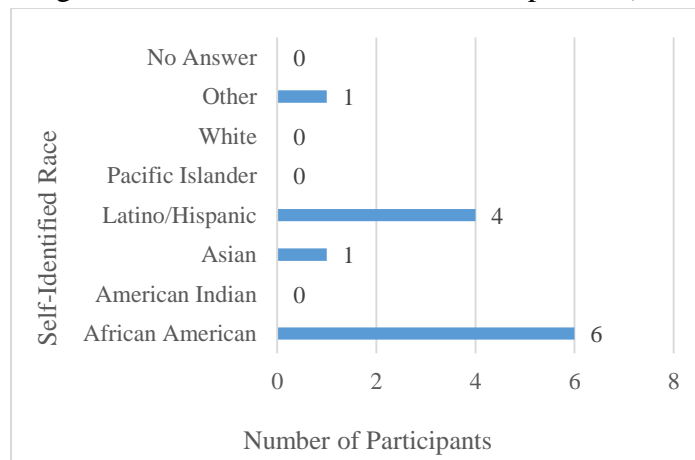
The focus group of undocumented participants (FG 1) primarily consisted of Latino/Hispanics (n=12). Figure 4 shows the breakdown of self-identification for this focus group.

Figure 4. Undocumented Focus Group Race (n=13)



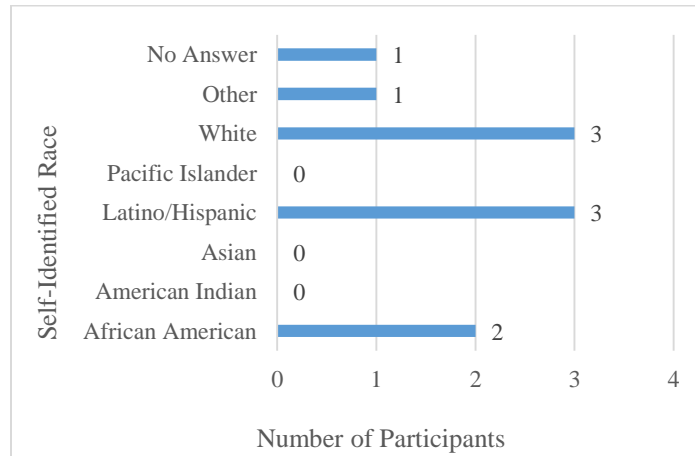
The focus group of women of color (FG 2) were primarily African-American/Black (n=6) or Latino/Hispanic (n=4). Figure 5. Displays information on all participants.

Figure 5. Woman of Color Focus Group Race (n=12)



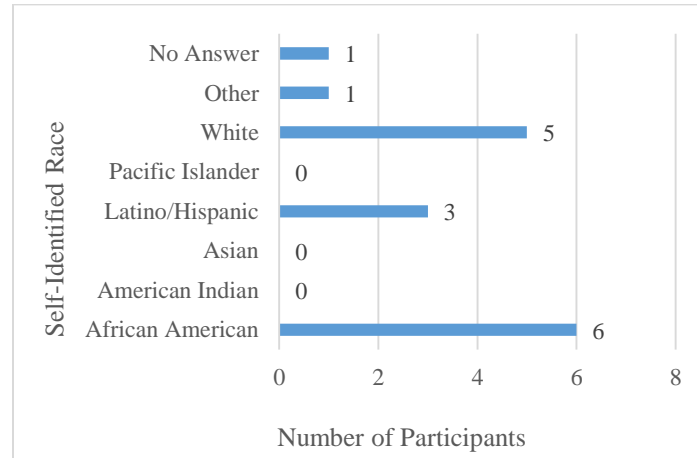
The aging/older adults focus group (FG 3) participants included those who identify as White (n=3), Latino/Hispanic (n=3), African-American/Black (n=2) and other. Figure 6 shows the complete breakdown.

Figure 6. Aging/Older Adults Focus Group (n=10)



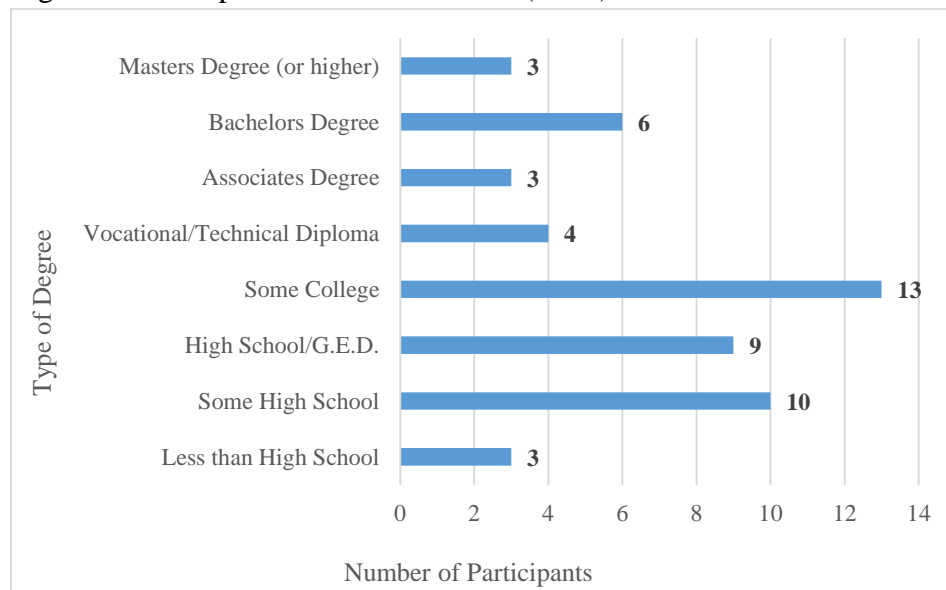
The majority of the Service Planning Area 1 focus group (FG 4) participants were African-American/Black (n=6), White (n=5), and/or Latino/Hispanic (n=3). Figure 7 displays all identifications.

Figure 7. Service Planning Focus Group (n=16)



Educational level varied with some college (n=13) being the mode, followed by some high school (n=10), and high school/GED (n=9) as the two next frequent categories. Figure 8 portrays the educational levels of the participants.

Figure 8. Participant Educational Level (n=51)



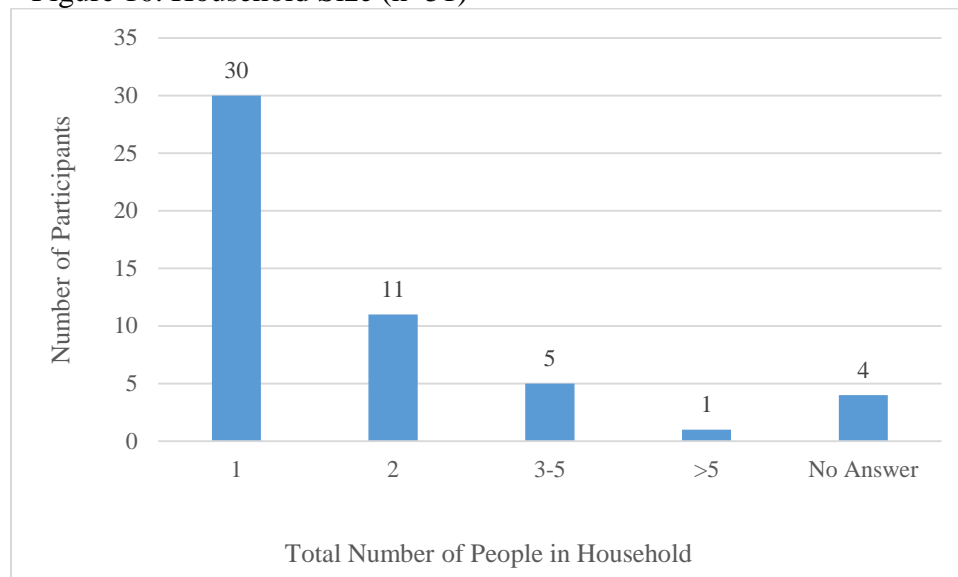
A majority of participants (n=40) earned \$15,000 or less a year. Only one participant claimed that they earned more than \$30,000 a year. Figure 9 displays the participant's self-reported income.

Figure 9. Participant's Income (n=51)



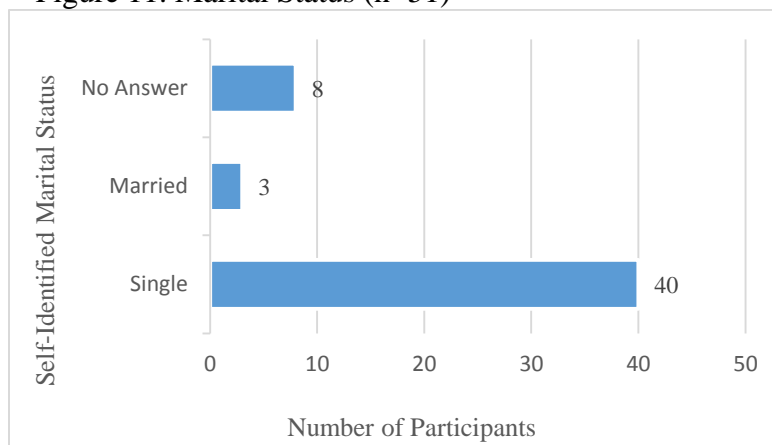
Many of the participants (n=30) lived alone. Figure 10 portrays the participants' household size.

Figure 10. Household Size (n=51)



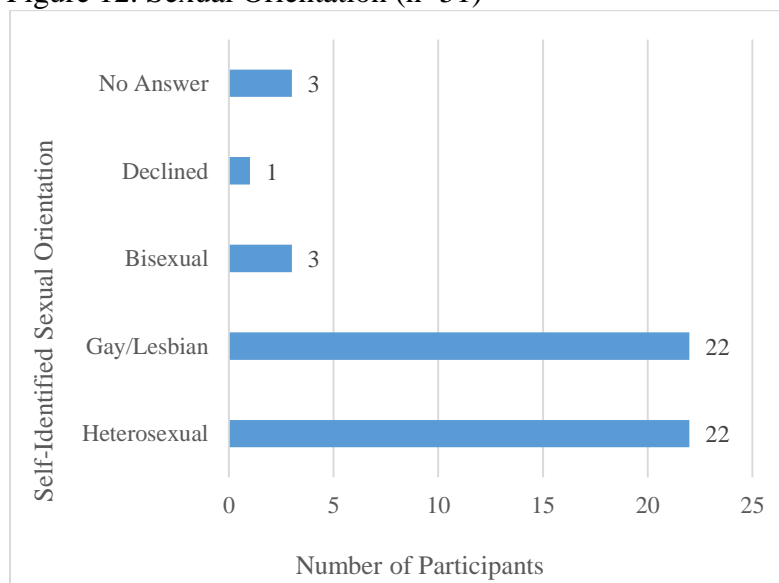
More than half of the participants were single (n=40). Figure 11 displays the marital status of the participants.

Figure 11. Marital Status (n=51)



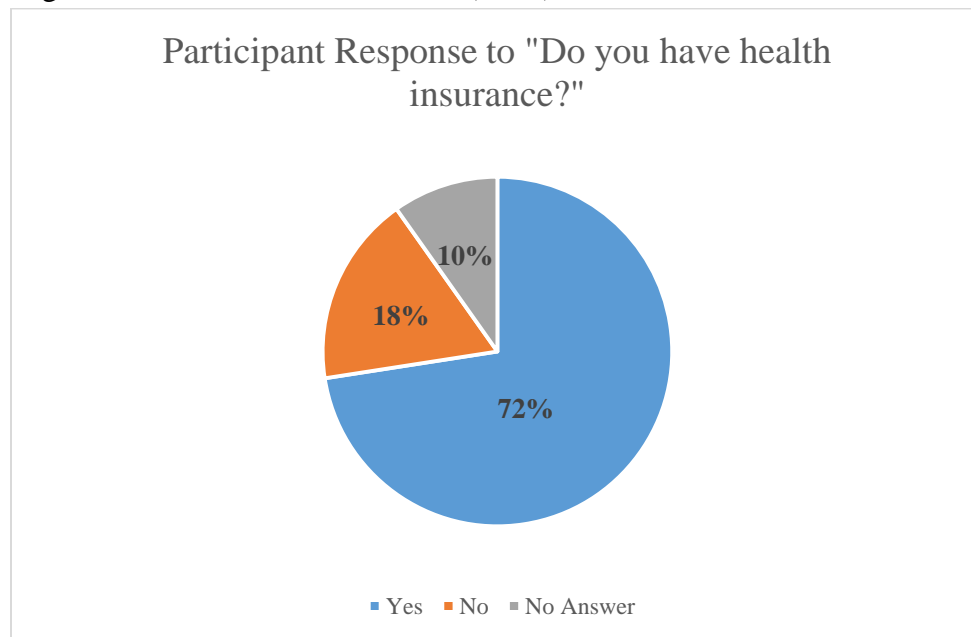
Heterosexual (n=22) and gay/lesbian (n=22) participants were both well represented. Figure 12 displays the sexual orientation categorization.

Figure 12. Sexual Orientation (n=51)



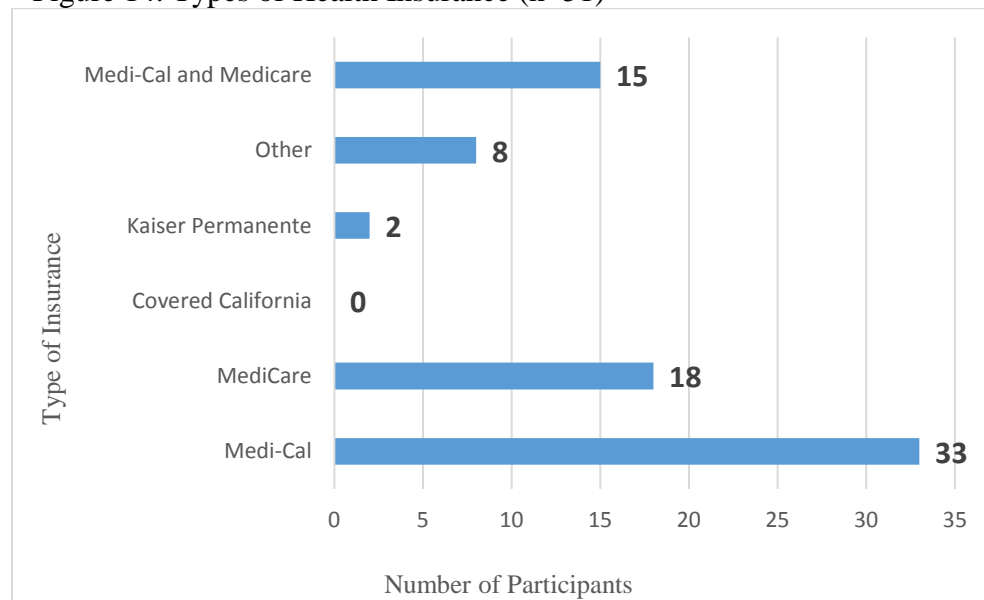
More than half of the participants (72%) have health insurance. Figure 13 portrays the health insurance status of the participants.

Figure 13. Health Insurance Status (n=51)



A majority of participants had either Medi-Cal (n=33) or MediCare (n=18). Fifteen people indicated having both Medi-Cal and MediCare. The types of insurance reported are shown in Figure 14.

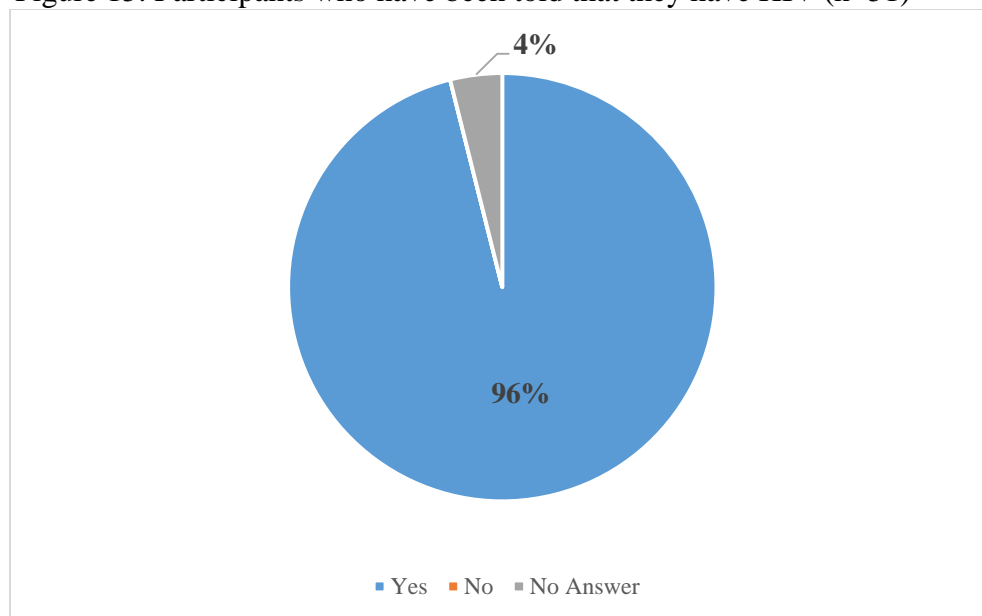
Figure 14. Types of Health Insurance (n=51)



*Note: This is a check all that apply option so total is greater than number of respondents.

Almost all (96%) participants reported having been told that they have HIV. Other respondents declined to answer. Figure 15 shows all responses for this question.

Figure 15. Participants who have been told that they have HIV (n=51)



The number of years a participant was diagnosed with HIV ranged from 41 (2%) to 2 years (2%). The average number of years living with HIV was 20.0 (SD = 10.24). Table 2 portrays the breakdown of the amount of years the participants have been diagnosed with HIV.

Table 2. Years Diagnosed with HIV (n=51)

	Frequency	Percent
2	1	2%
4	1	2%
8	3	6%
11	3	6%
12	3	6%
13	1	2%
15	2	4%
16	2	4%
17	2	4%
18	4	8%
19	2	4%
20	1	2%
22	3	6%
23	1	2%
24	3	6%
25	1	2%
26	1	2%
30	1	2%
31	1	2%
35	1	2%
36	1	2%
41	1	2%
Mean	20 (SD=10.24)	

In the undocumented focus group (FG 1), the number of years a participant was diagnosed with HIV ranged from 23 (8%) to 2 years (8%). The average number of years a participant has been diagnosed with HIV is 13.9 years (SD = 7.34). Table 3 displays the number of years a participant has been diagnosed with HIV.

Table 3. Undocumented FG – Years Diagnosed with HIV (n=13)

Years since diagnosis:	Frequency	Percent
2	1	8%
4	1	8%
8	1	8%
11	1	8%
15	1	8%
17	1	8%
18	1	8%
19	1	8%
22	1	8%
23	1	8%
No Answer	3	23%
Mean	13.9 (SD = 7.34)	

In the woman of color focus group (FG 2), the number of years a participant was diagnosed with HIV ranged from 30 years (8%) to 12 years (17%). The average number of years a participant has been diagnosed with HIV is 20.4 (SD = 6.99). Table 4 shows the number of years a participant has been diagnosed with HIV.

Table 4. Women of Color FG – Years Diagnosed with HIV (n=12)

Years since diagnosis:	Frequency	Percent
12	2	17%
16	1	8%
20	1	8%
24	2	17%
30	1	8%
No Answer	5	42%
Mean	20.4 (SD = 6.99)	

In the aging/older adults focus group (FG 3), the number of years a participant was diagnosed with HIV ranged from 35 years (10%) to 11 years (10%). The average number of years a participant has been diagnosed with HIV was 23.0 (SD = 8.14). Table 5 displays the number of years a participant has been diagnosed with HIV for that group.

Table 5. Aging/Older Adults Focus Group– Years Diagnosed with HIV (n=10)

Years since diagnosis:	Frequency	Percent
11	1	10%
18	2	20%
19	1	10%
22	1	10%
25	1	10%
31	1	10%
35	1	10%
No Answer	2	20%
Mean	23 (SD = 8.14)	

In Service Planning Area 1 focus group (FG 4), the number of years a participant was diagnosed with HIV ranged from 41 (6%) to 8 years (13%). The average number of years a participant has been diagnosed with HIV is 19.9 (SD = 9.77). Table 6 shows the number of years a participant has been diagnosed with HIV.

Table 6. Service Planning Area 1 Focus Group– Years Diagnosed with HIV (n=16)

<u>Focus Group on 5/2/2016</u>		
Years since diagnosis:	Frequency	Percent
8	2	13%
11	1	6%
12	1	6%
13	1	6%
15	1	6%
16	1	6%
17	1	6%
18	1	6%
22	1	6%
24	1	6%
26	1	6%
36	1	6%
41	1	6%
No Answer	2	13%
Mean	19.9 (SD = 9.77)	

The average number of services per person currently being used is 4.59. The top two services currently being used are HIV medical care (47%) and free condoms (33%). The following services tied for third place at 27% for currently usage: helping getting enrolled in health insurance, HIV prevention education, and STD prevention education.

Participant's responses to "What kind of services are you currently using now?"		
Service:	Frequency	Percent
HIV medical care	24	47%
Condoms (free)	17	33%
Help getting enrolled in health insurance	14	27%
HIV prevention education	14	27%
STD prevention education	14	27%
Medical case management services	13	25%
Food bank/home-delivered meals	13	25%
HIV testing	11	22%
STD testing	11	22%
STD treatment	10	20%
Oral health services (general)	10	20%
Medical nutrition therapy	10	20%
HOPWA program services	9	18%
Mental health services (psychiatry)	7	14%
Medical transportation services	7	14%
Mental health services (psychotherapy)	6	12%
Other housing services	6	12%
Language services	5	10%
Home and community based services	4	8%
Non-medical case management (linkage case management, benefits specialty)	4	8%
Housing services (Residential Care Facility for the Chronically Ill)	4	8%
Referrals for services	4	8%
Other (Specify)	4	8%
Oral health services (specialty)	3	6%
Housing services (Transitional Residential Care Facility)	2	4%
Substance abuse treatment (residential)	2	4%
Substance abuse treatment (outpatient)	2	4%
Legal services	2	4%
PrEP (Pre-Exposure Prophylaxis)	1	2%

Outreach (linkage to and re-engagement)	1	2%
Average number of services per person	4.59	
Standard deviation	4.9	
Range [Min, Max]	[1, 24]	

The average number of services per person that the participants need but are having trouble accessing is 1.92. The top service that participants need but are having trouble accessing is legal services (16%). The second top two services needed (14% respectively) are medical nutrition therapy and non-medical case management (linkage case management, benefits specialty).

Participant response to "What kind of services are you currently receiving/needing but having trouble accessing/going to need soon?"	"I need but am having trouble accessing it."	
Service:	Frequency	Percent
Legal services	8	16%
Medical nutrition therapy	7	14%
Non-medical case management (linkage case management, benefits specialty)	7	14%
Oral health services (general)	6	12%
Medical transportation services	6	12%
HOPWA program services	6	12%
Home and community based services	5	10%
Housing services (Residential Care Facility for the Chronically Ill)	5	10%
HIV prevention education	4	8%
Oral health services (specialty)	4	8%
Mental health services (psychiatry)	4	8%
Food bank/home-delivered meals	4	8%
Other housing services	4	8%
Referrals for services	4	8%
Help getting enrolled in health insurance	3	6%
STD prevention education	3	6%
Mental health services (psychotherapy)	3	6%
Housing services (Transitional Residential Care Facility)	3	6%
PrEP (Pre-Exposure Prophylaxis)	2	4%
HIV medical care	2	4%
Medical case management services	2	4%
Substance abuse treatment (outpatient)	2	4%
Outreach (linkage to and re-engagement)	2	4%

STD testing	1	2%
Language services	1	2%
Substance abuse treatment (residential)	1	2%
Condoms (free)	0	0%
HIV testing	0	0%
STD treatment	0	0%
Other (Specify)	0	0%
Average number of services per person	1.94	
Standard deviation	2.02	
Range [Min, Max]	[0, 8]	

The average number of services per person that the participants will need in the next year is 0.69. The most common service that the participants reported needing in the next year is food bank/home-delivered meals (8%) followed by medical transportation services (6%).

Participant response to "What kind of services are you currently receiving/need but having trouble accessing/going to need soon?"	"I will need in the next year."	
	Frequency	Percent
Service:		
Food bank/home-delivered meals	4	8%
Medical transportation services	3	6%
PrEP (Pre-Exposure Prophylaxis)	2	4%
Oral health services (general)	2	4%
Mental health services (psychiatry)	2	4%
Housing services (Residential Care Facility for the Chronically Ill)	2	4%
Housing services (Transitional Residential Care Facility)	2	4%
HOPWA program services	2	4%
Substance abuse treatment (residential)	2	4%
Outreach (linkage to and re-engagement)	2	4%
Condoms (free)	1	2%
STD testing	1	2%
Oral health services (specialty)	1	2%
Mental health services (psychotherapy)	1	2%
Medical case management services	1	2%
Home and community based services	1	2%
Medical nutrition therapy	1	2%
Non-medical case management (linkage case management, benefits specialty)	1	2%

A. Experiences Obtaining HIV Care/Services

Doctors

Participants commented frequently about their doctors, highlighting both positive and negative aspects. For many, their experiences with their doctor was a supportive one that endures over years.

“My personal experience was excellent. I’ve met my doctor for 19 years and she continues to improve as a human being, really intelligent. She’s studied. I’m happy with her, really.” (FG1)

“There was a doctor that lasted a long time at the clinic I go to. I felt very comfortable with her.” (FG1)

For those who had negative experiences with their doctors, a chief complaint was failure to treat the whole person with all of their physical health conditions. Another common complaint was feeling treated like a lab report instead of a human being, the lack of personal connection during the visits, and the hurried pace of the visits.

“No, he just has a note and says: “your levels are fine”, but he doesn’t check me up. The old doctor did check this, my mouth, this one doesn’t and I don’t feel comfortable with him.” (FG1)

“the doctors only want to focus on your labs. You are your labs, anything beyond that, they’re not going to listen to. And so, that’s my biggest issue, is they don’t want to hear what it is that I have to say, how I feel with the side effects or what else is going on with me. And then that’s just been a huge struggle, is just getting them to hear what I’m saying, because if it doesn’t match my labs, then they’re thinking I’m a liar, and that’s a huge, huge problem.” (FG3)

“...when I was with my first doctor, as [name deleted] said, my first experience was snap snap snap, he wouldn’t even let me explain my symptoms or how I felt; it was one patient after the other and the other. I was barely diagnosed. So that and the fact that I was getting depressed led me to stop going to him because I didn’t like it.” (FG1)

Doctor Turnover

Doctor turnover was an issue for some, but something seen as a normal part of life, or normal part of the medical system, for others.

“...that depends; in my case, since they change my doctor every 2 years, out of 8 doctors I’ve seen, 2 are embedded in my memory because they did take the time and I felt that. They talked to me. They cared.” (FG1)

Other Health Professionals

Experience with other health professionals including receptionists, social workers, emergency room staff, chronic condition specialists (non-HIV) and oral health care varied and were identified as an area for improvement.

Various participants noted that hospital and emergency room staff, professional staff who should be aware of protocols, would out the patient's status to the room at large. This was noted as a problem among participants in SPA 1 particularly because distance to specialty care requires people living with HIV to turn to emergency room services if an HIV specialty care doctor is not in the area. Nonetheless, participants from various groups mentioned it as both a historic and current issue.

"I don't need everybody up [in my business]. You're messing with the wrong [unclear audio (U/A)] she shouldn't take you to the emergency room because I didn't come to the emergency room for you to put my business in there. I came to the emergency room for help. Next thing I know security comes." (FG4)

"They really do do that to us. They come in and they speak on our medical issue and they ask about the viral levels, [unclear audio (U/A)] our T-Cell levels, and say you in between 2 people who you don't want to know your business. Even when you're in my hospital. They admitted you in the hospital and say get in a room with somebody. They still come in there talking loud about your medication [unclear audio (U/A)] in a hospital they don't want to touch you and don't want to breathe the same air as you." (FG1)

"In 97, I had an opportunist disease. I got really sick. My family from Guadalajara got here; they thought I was going to die. So when I was really sick, one of my nieces asked 'Why is my uncle sick? What does he have?' the doctor said: '... he's being consumed by AIDS.' I was bedbound and didn't know what to do. But that's what he told my family; everybody found out. So I'm the one with AIDS, but I got over it in therapy. They still call me that, but it's not important anymore. I'm over it, but it was terrible to me. [U/A]. I don't have any family here, but I get support from the groups, my friends." (FG1)

Appointment Timing

Various patients mentioned the need for additional appointment time, or that the visit was too short or impersonal.

"Going back to the original question of how can the doctor-patient relationship improve, I think they need to give us more space as patients because it's illogical that they make you wait 2 hours to see a doctor that will only see you for 20 minutes. The commute takes longer than the meeting with the doctor." (FG1)

Health Care Access

Health care access is closely linked with issues stemming from insurance company practices. Issues raised that were barriers to access included the need to go through their primary care provider first for other types of care, a diminished ability to access providers of choice (particular doctors or institutions), less services being offered (e.g. support groups or child care no longer available) or available at fewer places. Prohibitive costs for care and medications were also serious issues that often led to the inability to follow all recommended treatments.

“I go to the Woman’s House. I was going to the one that’s a hospital for years and years and years. Was going to the programs there, the Wise Study, [U/A]. And now they say I can’t go there no more. They won’t accept me ... Because once Obamacare came along, it changed everything. You can only go to your primary doctor. Because I used to go to the clinic down the street from my house and went down there. They said ‘Oh no, you got to go to your primary doctor.’

Moderator: But can’t you change your primary doctor?

...

But I don’t want to change my primary doctor, because then you got to go through the process of getting the note in, they all up in your business, just want to know what’s going on, why you here and blah blah blah. So I’m staying with my doctor because they already know all this information. And I don’t want my information all over, going God knows where and lost. And I don’t have no problem with my doctor, I just have a problem with the receptionist, but I’ve got that under control. But other than that, I don’t have no problem with the pharmacy.” (FG2)

“I’ve been in the country for a little while. It’ll be 5 months, I think, so I’m just getting familiarized with the services you offer. ... The only issue I’ve had at the services is the schedules. I know I can find other agencies that have more accessible schedules and stay open later, but why should you look for anything else instead of improving the one that’s already there, nearby. I could go half across town for a meeting with a doctor, but that implies money and a ton of things. If you already have it, you should improve that service, right? So the only thing I’ve struggled with is that: since they close at 3:30pm, I get off at 3 and I barely make it there. But the doctor has been very accessible and cool. He waits for me and helps me. But that’s the only thing that’s taken some struggle.” (FG1)

“People are getting lost in care because of the fact it’s strictly medical, so then who connects you to housing, I’ll say [U/A], mental health, who? Social security, who tells you exactly where to go? I live in South Bay, I went all the way to West Hollywood because HIV friendly to the social security office quote-unquote ‘just a place to go’ but yeah, you have to just ask people that are working, some of the most old-timers have been up there for a while, you get as much information as you can from them because they’re getting read, just like you said things are ready to change and I believe that county clinics are going to be the first to go.” (FG2)

Accessing Health Insurance

Access to health insurance varied. Most participants had Medi-Cal or Medicare or both. Others lacked health insurance entirely, and still others had private managed care insurance or subsidized managed care health insurance through options opened after the Affordable Care Act. Participants brought up a host of positive and negative experiences with Medi-Cal and/or Medicare, but it was more positive than negative. Of note, one of the few who had private insurance (Kaiser) had a negative and stigmatizing experience.

“I wanted to share that one of my first negative experiences when I was diagnosed 16 years ago was how they notified me that I was HIV-positive. And I don’t know if the doctors have changed their procedures, but every time I go I have to, I’m employed, so I have a job and I have Kaiser Insurance. And one of the reasons I started looking for work is because I don’t want to have Medi-Cal and resort to all having one doctor and when he’s out of town, the treatment stops. So I got a job and I have Kaiser, but the shame and the stigma that the staff demonstrates to HIV-positive, or if you have an STD is embarrassing. Doesn’t even want to make me go back to Kaiser. And I have good insurance. So I’m always complaining with the staff, you know, and those are the negative experiences that I’ve had in the last 16 years.... the stigma that they place on people that are HIV-positive or if you have an STD or a new STD, you know, is crazy. It doesn’t make me want to go back to Kaiser, you know? ...I had, because I live with syphilis as well, and so my titers were going up and they’re like, ‘Oh, you must have been re-infected with a new strain of syphilis.’ And the nurse said: ‘I don’t want to see you here in this room and give you more penicillin shots. This is the bad room. And the next time I’m going to spank you.’ And she was playing around, but I was like ‘You don’t know me to be playing around like that. You’re making me feel bad that I’m having sex...’” (FG2)

Communication with providers, particularly for those participants requiring multiple providers was an issue compounded by insurance company processes. Moreover, the paperwork required by insurance companies themselves was confusing to many. Inter-provider care was a critical issue for many participants so eliminating or streamlining third party intermediaries like insurance companies might alleviate some of these problems.

“I just need to be into one setting. I don’t want to go all over town just to see about this problem that I’m having and then another problem that I’m having, and then you know what really complicates that situation? Is that either one of the doctors don’t even communicate together and I can go to either of them and say ‘did you get that report for the... he said he was gonna pass it over’ and he says like ‘What report? who is this doctor?’ and then I go over to the next ‘Did you pass that over to them?’ ‘Oh, well, what doctor was that?’” (FG3)

“... you get a form in the mail, and says: ‘L.A. Healthcare something’, and you’re like: ‘who are they?’ and then you call the number, and then they say a different name on the phone,

and you say, you ask them: ‘Are you part of Medicare?’, ‘No, we’re part of...’ ‘Is that part of Medi-Cal?’, ‘No.’ ‘Is that part of Care First?’ which is my health insurance, ‘No’. And then it’s like, and then, okay, you’re not part of anything that I’m part of, so where do I go from here? And that’s, for me, where it gets to the point of, how do you function? How do you get anything solved when the people you’re getting letters from don’t even know? They don’t know what letters are about, first of all, you don’t know who they are, there’s so many things, levels, of bureaucracy and everything, you are behind all these forms that you get, it’s maddening.” (FG3)

“... the paperwork is astoundingly uninformative, this piece of paper, and once... it says it’s talking about A, but it’s really talking about Z, and then wanting to do D, and you call to find out what’s going on, and then you get someone who’s an answering service to forward the call and no one has anything and I’m one of the most persistent people in... my therapist says I’m at the top of the list, and if I’m frustrated and having an issue, I can’t even imagine how difficult it could be with someone dealing with this who, does not have the time, or gets tired and fed up”(FG3)

Transportation and Proximity

Transportation and proximity were two related issues that arose. In terms of location, transportation was particularly difficult for SPA 1 residents as they were farther from services, and had limited access to specialists. Many had moved to SPA 1 for availability and affordability of adequate housing. When referred to services at various locations, access to transportation coupled with the time needed to travel across town as well as office hours for services became compounded issues. The extra time required for accessing services at disparate distant locations also conflicted with work schedules for some.

“My problem is the whole transportation issue because I live off the grid, in the mountains, and I have to drive 39 miles to get medical care when I have a high desert clinic 13 minutes away from me, but they don’t have a ... specialist that specializes on HIV. So I have to drive 39 miles just to get care. And before I even had a car, I used to have to sit at my boyfriend’s auto body shop all day because I would have to ride with him down into town just to go see the doctor in Cedar Hills and he would shop in Lancaster. And the bus, I have to call and set up an appointment and that’s like 18 miles walking across the desert just to get to that bus stop where they pick me up at. So my issue is transportation and they also have a whole bunch of people who live that way in my area, and the van don’t go that far. And if they don’t have transportation, no family support or no outside support that can give them a ride to take them halfway to meet that van, they won’t get into care.” (FG4)

“right now I’m seeing like two doctors, and I really don’t care for either one of them, you know. I don’t know, because I need to be where I can be in one facility getting everything done, you know. Instead I’m still running to this doctor way across town, the other one back down in Georgia [U/A] you know, I’m just tired of that type of runaround.” (FG3)

“but for my doctors and everything, it doesn’t matter how long it takes me to go back to L.A. [from SPA 1], but I would never change that because I have everything in the same spot.” (FG4)

Availability of Specialty Care

As those living with HIV age, they are faced with multiple chronic conditions. Coordinated care and treatment of all conditions becomes more critical. Therefore, there is a need not only for specialty care but coordinated specialty care. Other participants commented on the perception that the availability of HIV specialty care is declining, resulting in shorter visits, more patients per doctor, and less days/time available.

“So what I would suggest is for them to give us more time to know what other needs or concerns we have besides HIV, because it’s not used HIV, but HIV-related stuff. Not only HIV affects you, but other things. For example, in my case, since you’ve passed this age, you need these studies. And unless you ask for those, they won’t offer them to you. I noticed that because I read, I stay informed, ‘hey doctor, because of my age, I think I qualify for this.’ ‘Oh, that’s true. Yes. I’ll order them.’ I don’t have to tell him; he needs to tell me. He’s the expert, you know what I mean?” (FG1)

“being in my 50s and growing older, which is great, but I have an easier time with getting my HIV dealt with than getting a colonoscopy....then on top of that, you got other things that are either amplified with HIV or ‘oh, you’re more prevalent for’ [U/A] things like that; teeth issues.” (FG3)

Medication Coordination

Coordination of medication across specialists for different types of conditions was also mentioned. Other medication issues included side effects (short and long-term); lack of knowledge among providers, users and their social support caretakers; cost; and long-term impacts such as oral health issues.

“We just have a doctor, an HIV doctor once a week. If we get sick, we go to the emergency room. I go to emergency many times, but they just give me like a [U/A] they charge for everything we access right here, they just want us for the money. We don’t have another HIV doctor, ... you go to the hospital and each time they use a medication that has nothing to do with your body because you take HIV medication and there’s a difference, it doesn’t work with that...” (FG4)

“when you take a medicine and let’s say you have a chronic disease and I’m not talking about HIV ‘cause chronic can be kidney or in testicle, it will tell you on the prescription “do not take this medicine”, well, why do the doctor give it to you?” (FG3)

“wondering what, okay ‘I’m walking and I’m slipping, am I gonna break something?’ and then it’s gonna be ‘is the healing going to be compounded by...Or, if that’s adding you can’t

take this medication because that will harm your healing’. So, doing that juggle and having someone who understands that and can explain it both to yourself and family who want to help but don’t know what they’re doing.” (FG3)

“medication is really horrible, it really is. It gives you more problems just having HIV, you are beginning an experience other things.... You should be able to take your medication without having to go through another trauma.” (FG3)

Language Barriers

This issue was only brought up in the Spanish language group, but was a prevalent topic within that discussion. Many of the participants felt that they were less connected to their doctor and other health care staff when a language barrier existed. There was no specific question that asked about language barriers; however, this topic was broached in response to the question about how it has been receiving HIV related services and care. One participant mentioned the language barrier as in response to advice from a fellow participant of how to advocate for himself with a doctor.

“He doesn’t speak Spanish. They always set up an interpreter for him. So, another issue, I prefer to have a doctor that speaks Spanish, but they don’t have one now.” (FG1)

The group also seemed to feel that having translators over the phone was not as effective as having another human being that spoke their language in the room with the doctor and during their time receiving health care.

“That’s what we need sometimes at the clinics because there are some doctors that don’t speak Spanish and sometimes their assistants don’t either. That’s what we need the most: to have interpreters next to the doctors. Sometimes there’s none.” (FG1)

Cost

The cost of multiple medicines was too high, leading to a forced choice between the recommended medication for some. Even with insurance, co-payments were very high, particularly for dental services.

“...When I get there they’re like ‘Ok, yeah, we take your insurance, but it’s going to cost you like almost \$2,000, \$900 for this, and this for that,’ and I was like why do you guys pay for, then? I thought you guys took my insurance.” (FG2)

“I’m on Medicare! But I’m only allowed 6 prescriptions to be filled a month and after that they get to tell you, you got to do [U/A] and like, I’m not supposed to be without heart medication. When they told me I had to [U/A], it’s when you have went over your limit on your medication and they have to get in contact with [U/A] to see if they can see if you really needed it, they are approved to get.” (FG4)

B. How Affected by HIV Status

Stigma

Stigma and rejection related to HIV status continue to be very prevalent. Stigma is experienced in all settings: when accessing health care services, in the workplace, among romantic relationships, among the general public.

With respect to the health care setting, stigma was mentioned. In particular, many mentioned that the way they found out about their diagnosis and subsequent treatment was very stigmatizing. While for most the diagnosis was long ago, the comments were articulated with a pain that is still raw.

“Just wanted to add one thing: a lot of the connections to the county hospitals, the diverse frustration of the wait time, the frustrations of how they’re treating you, like they’re going to put you in a contagious infectious ward, put on masks and curtains and everything. It’s just a different treatment.” (FG2)

Participants across groups mentioned comments from health care providers inferring denial of care due to HIV status, including oral health care, fertility treatment and kidney transplant needs.

“it was 2014, I was going through infertility because I was diagnosed with PCOS, Polycystic Ovarian Syndrome, where it was hard for me to ovulate, so I needed assistance in getting pregnant. So my doctor referred me to the reproductive endocrinologist and they did all the workups, they did the labs, I went through all these procedures, [U/A] and all this stuff, so when they gave me the results, they went, ‘oh, you know you’re HIV positive?’ I’m like ‘yeah, I know I’m HIV positive!’ ... So I did all these workups for months and when it was time to do the actual insemination, because I had to do intrauterine insemination, and when it was time for my appointment to do that insemination, then people called me and said: ‘we can no longer assist you because we don’t have a donor [U/A] in this facility.’ And I literally went, I lost it. I was in the mental hospital 5 times after that.”(FG4)

Many experienced stigma from the general public, both past and present, leading many to self-isolate and also prompting participants to request general information or campaigns about HIV for the public. Stigma from the general public ranged from verbal abuse to direct interpersonal violence or attempts to evict neighbors.

“I’ve been positive for 18 years and I asked this guy for a light so I could light my cigarette, it was him and his girlfriend. She said, ‘No, you got AIDS!’ and she spat at me! And I had to stand back. You know, because I have sciatica, because I got all these neurological problems I’m not like I used to be. Would I be able to knock her out or would she knocked me out? So I stepped back, took a deep breath and said, ‘Lord, get me around this corner,’ you know? And I’ll be ok. That’s the first time that I’ve ever, ever experienced that and I’m not

ashamed that I'm HIV-positive, because I was a national speaker, but this, the way it is, it was like what? This has never happened to me before, you know? And what do you do with a situation like that? This was in Lancaster. Downtown Lancaster.” (FG4)

“I was discriminated so badly because [U/A] he said to me: ‘no, no, no, no, that’s for seniors,’ he said. ‘If I do your haircut, that’s one more problem to us.’ Meaning [U/A] It made me feel so bad.” (FG4)

“We need to have more resources not just for us but for the general public. Where do you find HIV 101 course?” (FG4)

“I have to be careful even in what kind of details I use, we are in 2016, like what’s going to happen if I use your plate. So what we need in here is more education, [and] more [support] groups.” (FG4)

Family or Social Network

Family support for participants included the spectrum from highly supportive (e.g. providing housing, on-going care) to extremely ostracizing (e.g. taking legal action to prevent interaction with grandchildren due to HIV status). For those for whom family was supportive, the family unit was the primary source of care and needed support services for the participant. For those for whom family members were not supportive, close social or friend networks filled that role. Those without either type of social support were more likely to be homeless and have greater support needs overall.

“but worst of all is my family. My family doesn’t let me come over their house. My family doesn’t let me see, a couple of them, I got a couple of grandkids. I don’t get to see, talk, speak, or anything with my grandkids. That’s the worst of it all. That’s what really cut me deep ... To see your own family get in cahoots with Children Services to figure out a way to write it up to where I’m helpless to my own damn grandkids.” (FG4)

“my family raped me and now it turns out I’m an HIV positive. They helped me on the first, the first time I’d been to a hospital. ... because I had a severe fungus in my blood, instead of HIV. And also, they were fine with me, but after that they said, ‘Okay, you need to find a place’, then my brother, my older brother, he told me, ‘You can consider yourself homeless, you’re not going to be [U/A]’, so that was the rejection from my family.” (FG3)

“I’ve created a number of, what I call “safety nets”, of, if such and such happens, then, if you don’t hear for me within, if you call me, if you don’t hear from me within two days, call me again, then there’s a problem, or something happened, or whatever. Or with doctors, if this happens, I’ve created my own little domino effect, because I know if there is a problem, I live alone, I make sure friends and family... who has keys to the apartment? Who has...? Here’s where I keep papers and everything that you will need. Here’s that stuff. So I’ve

created that safety net and one time I was hospitalized and my safety nets all clicked into place and the social worker of the house was like: “Oh my god, how does this happen?”, I was like, ‘Yeah. It’s worked. Thank God.’ (FG3)

“A month after my diagnosis I had told my family; I laid my cards to see if I was accepted or rejected. Thanks to my conversation with my family, I spoke to my friends the next day. They all accepted me, just like you. I have a lot of support from my family and friends. That’s what helps you grow emotionally and to work for others who can’t face it.”(FG1)

Dating/ Significant Others/ Social Relationships

While there were some positive stories, rejection was a prevalent fear and reality, for both the general public interaction as well as more romantic, personal or intimate relationships. Personal strategies for facing this reality varied from celibacy to isolation, to full disclosure prior via on-line social dating sites, to “don’t tell if not asked.”

“I’m celibate too because at this point, living in Lancaster, they have broken some of my spirit that I had before. I just can’t tell people like I used to.” (FG4).

“I want to meet somebody and I want to date somebody that’s positive so we have that shared experience so then if we know that we decide to be in a monogamous, exclusive relationship and we both consult with our doctors and we want to make that decision to not use condoms, well then I know he’s positive and I’m positive even though that’s probably not, the medical community might not agree to it, but it’s between two mutual consenting adults and whatever him and I want to do in the privacy of our bedroom is our business.” (FG2)

“there’s a website online where you can meet other positive people called PositiveSignals.com, right? And I met some boyfriends that way.” (FG2)

“MODERATOR: What are the specific methods that you used to protect yourself and your wife?

MALE SPEAKER: Well, I use a condom. I mean, that’s all there is. I have a drug that I know that won’t get her pregnant because that’s the latest, the best drug that’s out today in today’s market, but still, I’m not willing to go rough-ride, to say.”(FG3)

“Well, you know, I was about honesty, I’m not going, if I’d be honest, [U/A]. I ain’t never getting none. So, I just started saying, “Well, they ask you no questions, I take you no asks”, and that’s how bad that was. If you don’t ask me, I’m not going to tell you. But if you ask me, I’ll tell you. “But always use safe sex”, but I’m not going to just put that disclosure out because of the rejection.” (FG3)

Disclosure

Disclosure of status varied by participants with many preferring to keep that information to a trusted few, but other public advocates. Some mentioned fear of violence, while others were sometimes hesitant to even check off a box on a form about status, given that the form could be seen by multiple others.

“We’re afraid to be exposed to the society [U/A] people in our neighborhoods, it’s very dangerous, they can do harm to us.” (FG4)

“...when you go and apply for stuff now they have that word on the form, you have to fill out an application. Like, I went to [U/A] foundation and every year I’m in the dental plan but every year I have to fill out a questionnaire and you know, they have HIV up there that’s as big as day, and I’m like “Wow, I remember when you didn’t see HIV on an application, you know? But since my dentist, she already knows I have it, you know, because I didn’t hide it. I told her I had it and so when I had to fill the paper out I don’t have a problem with it now, but in the beginning it bothered me.”(FG2)

C. Overall Education and Awareness about HIV and Services Available

Education

Education for the general public, family, friends, and allied health professionals was recommended most often in efforts to reduce stigma in and outside of the health care sector. Many participants expressed their frustration about the continued lack of education, especially after years from the early cases of HIV in the 1980s and 90s. Some participants commented on their struggles to educate others and the general public’s lack of understanding about how the virus is transmitted. The need for education was also referenced as a form of prevention.

“People get sick, and like the lady said, you know, they’re isolated, they don’t know who’s positive and then if you do tell somebody you’re positive, it’s the education [U/A], the people right here, they ostracize you. How can you live in a place? That happened in early 80s and 90s, people was doing that. Here it’s 2016 and people still doing that because they’re not educated.” (FG4)

“but the biggest thing, it’s like we’re in a country on an island, all here by ourselves. People have absolutely no education and it’s before even medication came around. Even though this is still Los Angeles County, is like there’s another country. And that education aspect, these doctors how who do DDS, do and done shit, not understanding or treating you like a plague of some sort that’s airborne, they need to be educated and they need to be reprimanded for their behavior. So we do need to stick up for ourselves in that aspect. I’ve never experienced that but we need to start writing them up as doctors. And knowing that we have that option because it’s not just here that that’s happening. My ex-husband’s friend was getting ready to get surgery and he told her about my status, I told him: ‘Once I tell you, whoever you feel

you need to tell I don't care, because I want you to be healthy and I want you to get the support that you need. I can't give that to you because it's me.' The doctor, the surgeon told her to stay away from him because you never know how that disease is spread." (FG4)

"MODERATOR: So, going along, kind of with this topic, how do you protect yourself and others from HIV?

FEMALE SPEAKER 1: Educate them.

FEMALE SPEAKER 3: Educate them, yeah." (FG2)

"Yes, they are. I have had to explain it- I do not have AIDS. I have HIV. Then you got to sit and explain and after a while it's like, 'forget it.'" (FG2)

Advocacy

Many participants identified themselves as being their own advocates and advocating for the services they needed and wanted. However, they also referenced the importance of having other individuals, whether it be their health care provider or a relative/friend, as advocates, especially when they are not feeling well.

"I just have to advocate for that myself. I mean, seriously advocate. Kind of like, I wouldn't say demand, but show a reason why this is necessary all the way up to the director. And then the director to the other dentist in order for me to get the proper service." (FG4)

"What you just said, I'm like yourself in the sense of, you know, I rather navigate it myself. But, if you're sick, if you're not feeling good, if you have no energy or if you're having side effects, or you're dealing with anything, even if all you have to do is sign this piece of paper, and continue your medical insurance, you can't even deal with that, you know? So it sits there. And when you're at that stage, you've lost everything because you didn't even sign that piece of paper and mail it in on time, and nobody can understand that because you're the only one, you know, besides dealing with everything else, so, yeah, when I can navigate things by myself and be a voice for myself, I have no problem. But, when I have those days, that, you know, I can't even get out of bed, or I can't focus, or I can't see, or, you know, blah, blah, blah, then it's difficult, then I have to ask for help, you know? And a lot of times people don't have time to help you, you know?" (FG3)

Resource Sharing

More information about services available was recommended. Participants noted that current advertisement of services was ineffective, and that many were unfamiliar with the diversity of resources available. If patients were more familiar with services, they were more likely to access them and share the information with others. Participants were also particularly keen on sharing information about resources with each other. An example of resource sharing within the focus groups is included.

"They have them here, I think just their resources and their advertising is real bad the way they advertise their services, they don't know how to advertise their services. I just

want to talk to the supervisor and say, ‘Y’all need help. Y’all don’t know how to advocate and give us these resources, let us know these resources are available.’” (FG4)

“So, when I’m newly diagnosed there’s always somebody that had called somebody to find out and if they can get through this, they can get through this. I don’t speak Spanish but I understand a little bit and, you know, when I now know of my sisters who do speak Spanish to say ‘well, wait a minute, I got somebody for you’.” (FG2)

“Yes, I wanted to ask you is that Weight Watchers program free? Because I had weight loss surgery.

Female Speaker: It’s free, it’s free. I’ll give you the resources, I’ll give you the lady’s number. Another thing, I want to let you guys know that they have a camp for people living with HIV, it’s called ‘[U/A] the journey’ and if you guys want to go, I can...it’s in June for 5 days, it’s health and wellness.” (FG4)

D. Other Issues Raised

Housing

Access to housing was a critical issue raised by the participants without being asked directly about it. Some participants were homeless, and most lived in crowded housing conditions. Those with families on Section 8 housing mentioned lack of private space household members. Housing was seen as a precarious issue so if one had adequate housing, maintaining that was primary over access to near-by specialty services.

“There’s something that wasn’t mentioned and it’s important: housing. It’s terrible for those who are HIV positive and undocumented. That’s where we need more support. I’ve been looking for an accessible place to live for years and the agencies haven’t been able to help me either. When they say they do, they ask for my earnings and say I need to make more. If I earned more, I wouldn’t be looking for housing assistance. It’s illogical really and it’s quite frustrating to be in a situation like this. I think the priority here is that HIV services have advanced a lot, there are a lot of services, housing is missing.” (FG1)

“I’ve been on disability since ’08, I’ve been having so many problems with housing and being able to pay for it because only get \$900 [U/A] pay your insurance, your car, food, it’s like if you’re in social security, I think you should get housing vouchers. It should go hand in hand.” (FG4)

“I came back to L.A., the center put me on medicines immediately, that was on 2007 and I was homeless. I got into Section 8. That took me, for the first available housing I could find, which was then across the board in Oregon. So, I moved to Oregon and I was there for a year and the townsfolk in Oregon eventually found out I was positive and they basically ran me out of town and I was still dealing with people down here in L.A. just asking very basic medical questions, “How are my kidneys” and the doctors up in Oregon were afraid. They

were like “we don’t feel qualified enough to answer whether your kidneys are good or not” and I eventually was transferred to Hawaii and right before I was to get on the plane, the landlord reneged and I lost my Section 8. I had three days to find something else, I couldn’t find it and so I moved homeless to San Francisco.” (FG3)

“Even with Section 8, I have problems. I have a housing grant through Housing Assist for People with AIDS. My Section 8 is through them. And I have an 11 year old boy, they gave me a one bedroom voucher. I got a one bedroom voucher, which is why I had to come out here because I got to make sure I got a bedroom for me and my son.” (FG4)

Work

Medicare/Medi-Cal insurance and other social security benefit stability like housing were sometimes more important than a job; making employment a detriment, particularly for those who can only work occasionally or part-time due to illness. For those with regular employment, the issue of having to hide their status for fear of job security or rejection was brought up.

“the moment that I was to document that I was HIV positive or AIDS or whatever, I wouldn’t be hired, even though California has the laws to protect, but I know, you know, in my field, that was suicide.” (FG3)

PREP and PEP

There was not a lot of discussion about neither pre-exposure prophylaxis (PreP) nor post-exposure prophylaxis (PEP). There was not a specific question nor prompt posed to the groups about either, but it was raised by participants in three groups. For two groups, the discussion surfaced when asked how they navigate their sexual health and how they protect themselves and others.

One person mentioned it in that he acts as a resource person to others:

“Well, I have different profiles online and at first I was very afraid to disclose my status. When I was going to therapy, my therapist recommended I did on at least one of my profiles to see what the result was. He said: “nothing’s gonna happen. Give it a try.” I was very scared. I was just starting to attend support groups, started to get more information, started seeing people, as they were saying, sharing your condition, which helps you to move forward. So, I decided to disclose it on one of my profiles. Nothing happened; in fact, I became an educator. They asked: “how did you get it? How do you deal with it?” etc. “What does undetectable mean? Or PreP?” So that’s what I do now, besides, and even if I am disclosing my status over there, I say I only do safe sex because there’s still a risk to infect someone or get yourself reinfected. You can get other STDs. So I’m very open: I’m undetectable, but I only practice safe sex. As simple as that.” (FG1)

A second mentioned use of PEP as a strategy, albeit an ineffective one:

“My experience when I learned that I had HIV, I went for the PEP, which is Post Exposure Prophylaxis, and they gave me a negative and they gave me the medication. I was on my 5th or 6th pill, I think, and I got a call and tell me I needed to come over. I knew then that something wasn’t right.” (FG1)

After this topic was raised, the moderator asked “Does anyone use PreP or PEP?” Despite the fact that these medications are meant for HIV negative individuals, two participants indicated that they had used both PreP and PEP, with both using PreP more extensively as part of a research study.

“So I was trying to have fun and not paying attention to the important things in life. ‘This will be an era,’ I said. So in order to protect myself I signed up for PrEP at UCLA because I wanted to avoid what happened. I took it for a year, before it went [U/A]. It only lasted a year because it was research. When it ended, like 6, 7 months later, I got it [HIV].” (FG1)

In the second group where the topic came up within the same context, the participant mentioned that the partner did not want to use PreP:

“So how I protect myself and others, I’m in a [U/A] relationship where my partner is negative. So I take my medication because he don’t want to take PrEP. He’s like, ‘If I ain’t got it, I ain’t taking no meds. But our treatment is prevention and you take your medication, then you keep taking yours to protect me.’ So that’s what I do, I protect, I take my medication to protect us both.” (FG4)

The use of PreP was discussed by both male and female participants of varied sexual orientations.

In the third focus group where PreP was mentioned, it was brought up as a resource-sharing comment at the end of the group when participants were asked to highlight important issues to them.

“The new injectable medicines, I’m not sure they’re doing stage 3 this year, it’ll be coming out in 2018, I’m going to be first in line to get rid of my pills. 2019, the injectable prep will be coming out, and then they’ve got like all this stuff that’s coming out with a cure.” (FG3)

E. Services Requested by Participants

Some highlighted funding for a cure as the preferred priority while others emphasized the need for addressing social determinants of health over biomedical strategies. With respect to social determinants, housing was identified in various groups as the critical issue

“ I’ve been positive since 1985 and I’ve always heard about cures coming soon, but haven’t seen anything. I’ve seen improvements, yes, but no cure. And I want to know who’s pushing

for the end of all this. This is what I want: see, there's this agency created so they can push someone to cure us." (FG1)

"The federal government is shoving more pharmaceuticals down our throat and coming up with more preventive medicines instead of finding the cure and they focus on the biomedical preventions rather than the education and the information and the social aspect, because they're not addressing the social determinants which is esteem, anxiety, depression, emotion, our spirit, our substance use, our affordable or lack of housing, child care, transportation, all of those are barriers to accessing." (FG2)

Support Groups

Support groups were one of the primary services requested and identified to be helpful. Many participants reported having had access to support groups previously, but that they were no longer available. A support group, primarily for women, was also requested. Participants mentioned that the support groups offered them a safe place to share their stories and to receive information. In addition to the support groups, participants also recommended having more social events to provide some emotional relief.

"I don't have much to say, I just would like to see more groups, more education because I think this is kind of like, I don't know how to say it, but we cannot talk about anybody about HIV because we're going to be out the circle..." (FG 4)

"we need a woman support group and also we need a support group for everybody. We don't have it anymore. And case managers. We don't have it." (FG 4)

"we need to focus more on refocusing our government funding to prevention and education services and social activities that brings up the self-esteem, brings up the self-love, brings up all the support and the community because that's all we have at the end of the day, is we have each other. The medical and the pharmaceutical establishments, I don't really think they really care about us. We're not another statistic, we're not another number." (FG 2)

Advocate/Case Managers

Having an advocate and/or case manager in the health care sector was also important for participants. Participants want someone who can help them navigate the health care system and link them to services. They also want someone with whom they can establish a rapport and who is knowledgeable of their medical history. Some participants mentioned having case managers before financial cuts, and reported their effectiveness in advocating and linking them to services.

"Well, I still think that is crucial to have an advocate in the hospital or in the clinic or wherever it is that someone is going to help you navigate these things when you can't. And even if that means [U/A] there with your physicians so you get your questions answered, or how do I, the simplicity of how do I even get my labs?" (FG3)

“You know, there used to be, before they started cutting all the funding was [U/A]. You could go to, you know, APLA or Asia Pacific AIDS and you had a coordinator that would help you and they knew you. They had a personable relationship with you and would say if you are so frustrated then you, then they would call the facility or with their voice they would say “hi, I’m calling from this organization or from the HIV Board on behalf of this patient, we want to get him in or they’re having a problem with Medi-Cal or where can they go now for housing or whatever” and you’d have that advocate. That’s all they cut away, you know? Then you’re just left out on the streets now. So, that was a big, big help because they were the ones who were up to date of what’s going on- “they’re sending treatment, they’re sending funding, oh, you need a new bus pass? Oh, you need this? Oh, we’re gonna have something social. This is a list for dentistry, this is a list for psychiatry and this is support group or even if you need personal counseling, we’ll set you up, you need a home visit” you know, all that’s gone, okay? Because HIV and AIDS doesn’t get the government funding anymore, you know.” (FG3)

Community/Wellness Center

A community health or wellness center was requested to access services such as exercise and nutrition classes to maintain a healthy lifestyle. Participants mentioned that services are currently provided in different locations spread throughout the city, which makes it more difficult to access those services. Therefore, having one centralized location where health and wellness services can be provided is needed.

“I feel that that’s cool that we all have places where we have to go, but why should we have to drive that far to get those services? Why? You know, why we have to drive that far when we live in a city that have all these services whether they spread it out or not. Why we have to drive far? Like, they have yoga. They have yoga for us. Free. Now you guys don’t even know about that, but they have health and wellness stuff. I contacted the L.A. Healthcare. Half of these people in here probably don’t even know Weight Watchers have a 20 week program where they give you coupons for 20 weeks so you can go to Weight Watchers and your case manager referred you out and they give this information, they give you these tickets. Every week for 20 weeks. And also, because I’m very resourceful and I advocate; don’t get me wrong, I advocate for you guys. Michelle, no. I’m a strong advocate to get these services across the 5 freeway. And they will come soon, you hear me? Soon! So APLA, L.A. Healthcare, they care for our health and wellness services like they have in L.A. where they show you how to cook your dinners, eat fresh meals, they can’t do that because they don’t have a community center here. And you know we can’t get these services.” (FG 4)

Participants brought up healthy lifestyles and self-care practices for both mental and physical health as central to the wellbeing. These included personal strategies of maintaining a positive spirit or attitude, exercising, relieving stress, and maintaining mental health through social support. A sense of gratitude was also articulated across groups.

Mental Health Services

Improved access to mental health services was mentioned throughout, however was of greater concern for participants in SPA 1. For participants in SPA 1, access to any mental health specialist was either not available at all or too far. Participants also expressed their need to see mental health specialists that are closer to them in order to maintain their treatment.

“We don’t have nowhere to go, like I need to go see a psychiatrist but we don’t have one, we have to go all the way to L.A. because we don’t have it in Lancaster” (FG4)

“I’d like to see better psychiatric services, at least once or twice a month. Because it doesn’t require that you go on a weekly basis. At least not having to go to LA all the time, because that is a really rough trip to go.” (FG4)

Discussion

In analyzing the transcripts, the authors noted evidence of resiliency or the ability to recover from disruptive change or misfortune without being overwhelmed or acting in dysfunctional or harmful ways. It was expressed in every focus group. In the group with people living in the US without standard documentation, many had come seeking refuge for sexuality-related identity and health care related issues. Even though they lived in precarious circumstances that are often deleterious to health, on balance they were grateful for improvements in their lives due to increased acceptance and availability of services.

“I want to say that the acceptance that we have because we’re Latino, we’re gay, and we live with HIV, and feeling accepted relies on the society we live in. The say that we live in this city changes all of our perspective. If we lived in the places we’re from, the stigma and the way we would be treated would be totally different. I think it’s a blessing for all of us to be here because we can see the progress. People care about it. A progress of the whole community, which is reflected in the treatment we all get as equals.” (FG1)

“I’m very thankful for this round table that’s for feedback. I’m very thankful for the health services you provide for people with HIV and maybe you want to know its defects. These are our points of view. Thank God you want to improve. So that’s it, I’m thankful for the services you provide in the county. I don’t know where the funds are coming from or how this works, but I’m very thankful.” (FG1)

Appendices:

Appendix 1. Demographic survey (English and Spanish)

Appendix 2. Focus Group guide (English and Spanish)

Appendix 3. NCLR/CSULB Center Background



LOS ANGELES COUNTY COMMISSION ON HIV

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Community Engagement Task Force Listening Sessions (Updated 3-20-16)

Demographic Questionnaire

Thank you for sharing your ideas and feedback on how we can improve HIV services in Los Angeles County. This questionnaire is intended to collect important information that the Commission on HIV needs in order to understand the service gaps and opportunities in our community.

I. Age

<input type="radio"/> 13-17 years old	<input type="radio"/> 40-49 years old
<input type="radio"/> 18-24 years old	<input type="radio"/> 50-59 years old
<input type="radio"/> 25-29 years old	<input type="radio"/> 60 years and older
<input type="radio"/> 30-39 years old	

II. Race/Ethnicity (please check all that apply)

<input type="radio"/> African American	<input type="radio"/> Pacific Islander
<input type="radio"/> American Indian/Alaskan Native	<input type="radio"/> White/Not Hispanic
<input type="radio"/> Asian	<input type="radio"/> Other: _____
<input type="radio"/> Latino/Hispanic	<input type="radio"/> Decline to state

III. Gender

<input type="radio"/> Male	<input type="radio"/> Trans (Male to Female)
<input type="radio"/> Female	<input type="radio"/> Trans (Female to Male)

IV. Sexual Orientation: Do you consider yourself to be:

<input type="radio"/> Heterosexual or straight	<input type="radio"/> Queer/Questioning
<input type="radio"/> Gay, lesbian, same gender loving	<input type="radio"/> Other: _____
<input type="radio"/> Bisexual	<input type="radio"/> Decline to state

V. Educational Attainment (please check highest level completed)

<input type="radio"/> Less than high school	<input type="radio"/> Vocational/Technical School Diploma
<input type="radio"/> Some high school	<input type="radio"/> Associates degree
<input type="radio"/> High school or GED	<input type="radio"/> Bachelors degree
<input type="radio"/> Some college (did not graduate)	<input type="radio"/> Advanced degree (Masters and above)

VI. Income

<input type="radio"/> Less than \$15,000 a year	<input type="radio"/> \$25,000- \$30,000 a year
<input type="radio"/> \$15,000-\$20,000 a year	<input type="radio"/> More than \$30,000 a year
<input type="radio"/> \$21,000-\$25,000 a year	

VII. Marital Status

<input type="radio"/> Single	<input type="radio"/> Married
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VIII. Family Household: How many people are in your household?

<input type="radio"/> 1, just me.	<input type="radio"/> 3-5
<input type="radio"/> 2	<input type="radio"/> More than 5

- IX. Have you ever been told that you have HIV? ____Yes ____No
a. If so, when were you diagnosed? (month/year) _____
- X. Do you have health insurance? ____Yes ____No
a. If yes, what type? (please check all that apply)
____Medi-Cal ____Covered California
____Medicare ____Kaiser Permanente
____Other: (specify): _____
b. Do you have difficulty paying your premium or co-pay?
____Yes ____No

XI. What kind of services are you currently receiving? Check all that apply.

Type of Service	I am using now	I need but am having trouble accessing it	I will need in next year
<input type="checkbox"/> Help getting enrolled in health insurance			
<input type="checkbox"/> PrEP (pre-exposure prophylaxis)			
<input type="checkbox"/> HIV prevention education			
<input type="checkbox"/> STD prevention education			
<input type="checkbox"/> Condoms (free)			
<input type="checkbox"/> HIV testing			
<input type="checkbox"/> STD testing			
<input type="checkbox"/> STD treatment			
<input type="checkbox"/> HIV medical care			
<input type="checkbox"/> Oral health services (general)			
<input type="checkbox"/> Oral health services (specialty)			
<input type="checkbox"/> Mental health services (psychiatry)			
<input type="checkbox"/> Mental health services (psychotherapy)			
<input type="checkbox"/> Medical case management services			
<input type="checkbox"/> Home and community based services			
<input type="checkbox"/> Medical nutrition therapy			
<input type="checkbox"/> Non-medical case management (linkage case management, benefits specialty)			
<input type="checkbox"/> Medical transportation services			
<input type="checkbox"/> Food bank/home-delivered meals			
<input type="checkbox"/> Housing services (Residential Care Facility for the Chronically III)			
<input type="checkbox"/> Housing services (Transitional Residential Care Facility)			
<input type="checkbox"/> HOPWA program services			
<input type="checkbox"/> Other housing services			
<input type="checkbox"/> Language services			
<input type="checkbox"/> Substance abuse treatment (residential)			
<input type="checkbox"/> Substance abuse treatment (outpatient)			
<input type="checkbox"/> Outreach (linkage to and re-engagement)			
<input type="checkbox"/> Referrals for services			
<input type="checkbox"/> Legal services			
<input type="checkbox"/> Other: (specify): _____			



COMISIÓN SOBRE EL VIH DEL CONDADO DE LOS ÁNGELES

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www.hivcommission-la.info

Sesiones de intercambio de información de grupos de trabajo de participación comunitaria (Actualizado 3-20-16)

Cuestionario demográfico

Gracias por compartir sus ideas y opiniones sobre cómo podemos mejorar los servicios de VIH en el Condado de Los Ángeles. Este cuestionario está diseñado para recopilar información importante que la Comisión sobre VIH necesita para entender las deficiencias de servicio y las oportunidades en nuestra comunidad.

I. Edad

<input type="radio"/> De 13 a 17 años	<input type="radio"/> De 40 a 49 años
<input type="radio"/> De 18 a 24 años	<input type="radio"/> De 50 a 59 años
<input type="radio"/> De 25 a 29 años	<input type="radio"/> 60 años o más
<input type="radio"/> De 30 a 39 años	

II. Raza/Grupo étnico (por favor, indicar todas las que aplican)

<input type="radio"/> Afroamericano	<input type="radio"/> Isleño del Pacífico
<input type="radio"/> Indígena Americano/ Nativo de Alaska	<input type="radio"/> Blanco/no hispano
<input type="radio"/> Asiático	<input type="radio"/> Otro: _____
<input type="radio"/> Latino/Hispano	<input type="radio"/> Se niega a responder

III. Género

<input type="radio"/> Masculino	<input type="radio"/> Transexual (masculino a femenino)
<input type="radio"/> Femenino	<input type="radio"/> Transexual (femenino a masculino)

IV. Orientación sexual: Se considera:

<input type="radio"/> Heterosexual o hétero	<input type="radio"/> Queer (raro) /Indeciso
<input type="radio"/> Gay, lesbiana, amantes del mismo sexo	<input type="radio"/> Otro: _____
<input type="radio"/> Bisexual	<input type="radio"/> Se niega a responder

V. Nivel educativo (por favor, indicar el nivel más alto completado)

<input type="radio"/> Menos que el secundario	<input type="radio"/> Diploma de escuela vocacional/técnica
<input type="radio"/> Algo de la escuela secundaria	<input type="radio"/> Título de asociado
<input type="radio"/> Secundario o GED (Diploma de educación general)	<input type="radio"/> Licenciatura
<input type="radio"/> Algo de universidad (no se graduó)	<input type="radio"/> Título avanzado (maestría y más)

VI. Ingreso

<input type="radio"/> Menos de \$15,000 por año	<input type="radio"/> De \$25,000 a \$30,000 por año
<input type="radio"/> De \$15,000 a \$20,000 por año	<input type="radio"/> Más de \$30,000 por año
<input type="radio"/> De \$21,000 a \$25,000 por año	

VII. Estado civil

<input type="radio"/> Soltero	<input type="radio"/> Casado
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VIII. Vivienda familiar ¿Cuántas personas residen en su vivienda?

<input type="radio"/> 1, solo yo.	<input type="radio"/> De 3 a 5
<input type="radio"/> 2	<input type="radio"/> Más de 5

IX. ¿Le han dicho alguna vez que tiene VIH? ____ Sí ____ No

a. Si la respuesta es sí, ¿cuándo se lo diagnosticaron? (mes/año)

X. ¿Tiene seguro de salud? ____ Sí ____ No

a. Si la respuesta es sí, ¿qué tipo? (por favor, indicar todas las que aplican)

____ Medi-Cal ____ Covered California

____ Medicare ____ Kaiser Permanente

____ Otro: (especifique):

b. ¿Tiene dificultades para pagar su prima o copago?

____ Sí ____ No

XI. ¿Qué tipo de servicios recibe actualmente? Indicar todas las que aplican.

Tipo de servicio	Ahora uso	Necesito, pero tengo problemas para acceder	Necesitaré el próximo año
<input type="radio"/> Ayuda para inscribirme en un seguro de salud			
<input type="radio"/> PrEP (profilaxis previa a la exposición)			
<input type="radio"/> Educación de prevención del VIH			
<input type="radio"/> Educación de prevención de ETS			
<input type="radio"/> Condones (gratis)			
<input type="radio"/> Prueba de VIH			
<input type="radio"/> Prueba de ETS			
<input type="radio"/> Tratamiento de ETS			
<input type="radio"/> Cuidado médico de VIH			
<input type="radio"/> Servicios de salud oral (general)			
<input type="radio"/> Servicios de salud oral (especialidad)			
<input type="radio"/> Servicios de salud mental (psiquiatría)			
<input type="radio"/> Servicios de salud mental (psicoterapia)			
<input type="radio"/> Servicios de administración de casos médicos			
<input type="radio"/> Servicios basados en el hogar y la comunidad			
<input type="radio"/> Terapia de nutrición médica			
<input type="radio"/> Administración de casos no médicos (administración de casos de enlace, especialidad en beneficios)			
<input type="radio"/> Servicios de transporte médico			
<input type="radio"/> Banco de alimentos/servicio de envío de comidas			
<input type="radio"/> Servicios de vivienda (Centro de cuidado residencial para los enfermos crónicos)			
<input type="radio"/> Servicios de vivienda (Centro de cuidado residencial de transición)			
<input type="radio"/> Servicios del programa HOPWA (Programa de oportunidades de vivienda para personas que viven con SIDA)			



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Focus Group Questions and Guide (Updated 3-20-16)

Group maximum size: 15 people max per session

When: April 4, 2016 (6pm to 7:30 pm; 6 -6:30 pm check-in and answer demographic questionnaire; 6:30-7:30 pm focus group)

Target audience: Consumers of Ryan White services who are undocumented

Facilitator Duties and Expectation(s):

1. Set the stage (Cheryl Barrit or designee): Introduction of the Commission, its intention, and highlight some of the successes and opportunities for involvement and improvement in the work of the body.
2. Confidentiality: ***Set ground rules for safety and inclusion***, including the role of any commissioners in the room. Sample rules may include: cell phones on silent mode, what happens in the room stays in the room, step up step back, no cross talk, agree to disagree, and speaking from “I” statements.
3. Facilitation: Use guide to ask question provided, however, be mindful of emerging themes that may elicit more conversation or offer an opportunity for less participatory individuals to be included in the conversation.
4. Attendance (coordinated by Cheryl and staff in advance): Any Commissioner in attendance will be asked to support the process by observation and volunteerism through note taking and/or referrals; setup and clean-up facility, welcome and thank participants.

Focus Group Questions: Questions in BLUE may be eliminated for time considerations

1. Where would you go for your dream vacation? (**Facilitator note:** This is a warm up opportunity to get people thinking bigger.)
2. Describe your experience with obtaining HIV-specific medical care? Positive experience? Negative experience? Next question in blue can be used a prompt for question #2
3. What have been your experiences with obtaining HIV-specific services? (**Facilitator note:** This question includes opportunities to prompt attendees toward service types such as psychosocial, dental, transportation.) Where do you go to look for services?

4. Have you attempted to sign up for health insurance? What has been your experience? Are you receiving the service you need? If not, why?
5. How have you been affected by your HIV status? In what ways have you experienced disapproval or rejection that you believe may have been related to your status?
6. What is your relationship with your doctor? Do you talk about HIV? Sexually Transmitted Infections?
7. How do you protect yourself and others from HIV? (**Facilitator note:** This is an opportunity to learn how people are navigating their sexual health. Can incorporate abstinence, partner negotiation, condoms, treatment as prevention – counseling, testing, medication adherence, and other biomedical strategies)
8. When you try to access services, what issues or concerns come up for you? Has learning your HIV status changed the ways in which you access support? If so, how?
9. How can your doctors and other providers serve you better? (**Facilitator note:** This is an opportunity to talk about quality of care, language, and other potential barriers or tools do you think doctors and other support staff need to enhance clinical delivery.)
10. In thinking of the future, where do you want to be in five years?



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Guía y Preguntas para el Grupo de Enfoque (Actualizado 3-20-16)

Tamaño máximo del grupo: Límite de 15 personas por sesión

Cuando: Abril 4, 2016 (6pm a 7:30 pm; de 6 a 6:30 pm registraci3n y cuestionario demogr3fico; de 6:30-7:30 pm grupo de enfoque)

Dirigido a: Consumidores indocumentados de los servicios de Ryan White

Expectativas y Responsabilidades de los Facilitadores:

1. Crear el ambiente (Cheryl Barrit o personal designado): Introducci3n de la Comisi3n, su intenci3n, destacar algunos ejemplos del 3xito y de las oportunidades de participaci3n en el trabajo del organismo.
2. Confidencialidad: **Establezca las reglas de seguridad e inclusi3n**, incluyendo el rol de los Comisarios presentes. Algunos ejemplos de las reglas pueden incluir: los celulares deben estar en silencio, lo que pase en el grupo se queda en el grupo, participar activamente sin acaparar la discusi3n, no interrumpir, estar de acuerdo en discrepar, declaraciones que empiecen con “Yo”.
3. Facilitaci3n: Use la gu3a para realizar las preguntas, sin embargo, tenga en cuenta los temas que se presenten que puedan provocar m3s conversaci3n o brindar una oportunidad para que los participantes menos activos puedan incluirse en la conversaci3n.
4. Asistencia (coordinada por Cheryl y personal asignado): Se le pedir3 a cualquier Comisario presente apoyar el proceso mediante la observaci3n y el voluntariado a trav3s de toma de notas y/o referencias; instalaci3n, organizaci3n y limpieza del lugar, adem3s de darle la bienvenida y las gracias a los participantes.

Preguntas para el Grupo de Enfoque: Las preguntas en AZUL pueden eliminarse por falta de tiempo.

1. ¿Donde ser3an las vacaciones de tus sueos? (Nota para el facilitador: Esta es una oportunidad de calentamiento para que los participantes comiencen a pensar en grande.

2. Describe tu experiencia respecto al acceso de cuidado médico específico al VIH. ¿Ha sido una experiencia positiva? ¿Ha sido una experiencia negativa? La siguiente pregunta en azul puede usarse como introducción para la pregunta #2 .
3. ¿Cuáles han sido tus experiencias al obtener servicios específicos al VIH? **(Nota para el Facilitador:** Con esta pregunta se pueden ofrecer ejemplos como servicios psicológicos, dentales, de transportación, etc.) ¿Dónde buscas esos servicios?
4. ¿Has intentado inscribirte a un seguro médico? ¿Cuál ha sido tu experiencia? ¿Estás recibiendo el servicio que necesitas? Si la respuesta es no, ¿por qué no?
5. ¿De que manera te ha afectado tu estatus de VIH? ¿De que maneras has experimentado rechazo o desapruebo que creas estén relacionados con el VIH?
6. ¿Cuál es tu relación con tu doctor? ¿Hablan sobre el VIH? ¿Hablan sobre enfermedades de transmisión sexual?
7. ¿Cómo te proteges a ti mismo y a los demás del VIH? **(Nota para el Facilitador:** Esta es una oportunidad para saber cómo las personas navegan su salud sexual. Puede incluirse ejemplos como la abstinencia, negociación con la pareja, condones, tratamiento como prevención – consejería, pruebas, cumplimiento con los medicamentos y otras estrategias biomédicas)
8. Al intentar tener acceso a servicios, ¿qué problemas o preocupaciones tienes? El conocer tu estado de VIH, ¿ha cambiado la manera en que buscas apoyo? Si la respuesta es sí, ¿de que manera?
9. ¿Cómo podrían tus doctores y otros proveedores servirte de mejor manera? **(Nota para el Facilitador:** Esta es una oportunidad de hablar sobre la calidad del cuidado o servicio, el idioma y otras posibles barreras o herramienta que piensen que los doctores y demás personal de apoyo necesitan para mejorar el servicio clínico)
10. Cuando piensas en el futuro, ¿dónde quieres estar dentro de 5 años?